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Being a Home Owner

By Mike Hansen

Being a home owner means I am no longer paying rent and getting nothing in return. I finally have a place that holds all my belongings.

I feel a part of the community. I know my neighbors and they know me. We help each other. A few weeks ago during a storm, strong winds blew down a tree in my front yard. A neighbor saw me having a hard time sawing the tree with a bow saw, so he got his chain saw out and sawed the tree into pieces in no time. Then I gave him all the wood to use in his fireplace.

I feel more of an equal with my family and people in the community. Most people are homeowners - I am too. I feel that I have more to talk about with them. We share the same experiences - the good and the bad.

I feel a part of the community. I know my neighbors and they know me. We help each other.

Being a homeowner makes me feel proud. My family helped me paint. My house looks great. Everytime I fix something I feel proud.



Mike Hansen mows his yard.

Owning my own home hasn't been all glory. Snow removal can be a back breaker. Also, there's a lot to do. Sometimes the inside repairs are tough, but I can usually find someone for help or advice. Sometimes I worry how to pay for repairs. Most people are OK with payments - otherwise I save up.

But one thing is for sure: I never want to go back to not being a homeowner.

Mike is the president of the newly formed self-advocacy group People First of New Ulm. For many years, Mike lived in apartments. But on November 27, 1993, he moved into his own house.

Is Your House a Home?

by Walter Rupp

At a recent meeting of self-advocates in Minnesota, a group thought of words that describe a home. The group used words like freedom, choices, pride, community, and security. These are words that most people might use to describe what a home means. However, one word stood out that probably wouldn't commonly make the list of words used to describe a home: power.

The places where people in this group have or are currently living are segregated, congregated, highly regulated and structured. They are staffed in shifts and owned by another person, a corporation, or the government. The places are facilities, sometimes described as "home-like," but not very much like "home" if your definition of home includes choices, freedom, and power.

For persons living in these facilities, the power does not belong to the people who live there, but to the staff working in the "homes." The staff manage the "residents" care and comply with a slew of well-intentioned government regulations. The power also belongs to the individuals, corporations, or government agencies that own and profit from the facilities.

The power does not belong to the people who live in the "facilities", but to the staff working there.

While the movement from institutions to the community continues, the opportunity

to own or control one's own home is still quite rare for persons with developmental disabilities. There are approximately 70,000 people with developmental disabilities still living in state institutions in our country. Only 38% of all people with developmental disabilities live in places with six or fewer people. People with developmental disabilities are still living in facilities, not homes.

But things are changing. In several states around the country, people with developmental disabilities have the opportunity to own their own homes. A man in Minnesota, Mike Hansen, recently purchased his own home (See his article in this issue of Voiceprint.) In Michigan, a community living services program enables people with disabilities to either buy or lease their own home and make their own decisions about the supports they need. And an organization called A Home Of Your Own Alliance is working on the national level to fund projects that result in ownership, choice, and control of homes by people with developmental disabilities.

By understanding the issues and speaking out, self-advocates can help themselves and others with disabilities to have more control over where and how they live. Together, self-advocates can demand the closing of state institutions and other large facilities, and work toward having more power in the place we call "home."

Walter is the Community Organizer for Advocating Change Together, a self-advocacy organization in St. Paul, MN.

VOICEPRINT is published "bi-annually by Advocating Change Together, Inc. 1821 University Avenue, Suite 306-S, St. Paul, MN 55104-2804 (612)641-0297 **Editor:** Jerry Smith

Advocating Change Together, Inc. (ACT) is a nonprofit self-advocacy organization directed by and serving people with developmental and other disabilities. ACT helps people to speak for themselves and works to reduce prejudice by making the public aware that people with disabilities have a broad range of abilities. ACT is committed to improving the quality of life for all people with disabilities in the least restrictive work and living conditions.

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Agencies and Housing Options

by Tom Fitzpatrick

There are many agencies that serve people with disabilities. It's a big business and it's getting bigger. In my opinion, the better agencies are not better because they do well on licensing inspections; it's because they truly respect and support the people they serve.

The area of housing is a good example, in the past, agencies owned or rented many places where people with disabilities lived. These places were often called *facilities or residences*, and the sizes of these places were indicated by the number of beds, not the number of people who lived there. Agencies controlled and operated these places with generally good intentions, but often without really listening to the people they served.

In recent years, many agencies have changed their way of thinking. Agencies are trying to figure out how to support each person they serve as a unique individual and how to help each person live in a way that best meets their needs and wishes.

Examples of this "person-centered" approach include agencies helping people with disabilities to buy their own homes, rent their own homes or apartments, choose the people they live with, choose the staff who

work directly with them, and find ways to make the places where they live feel like a "home."

Buying a home is a very complicated process. Agency staff have assisted people with disabilities in dealing with realtors, banks, mortgage companies, and government housing programs. And after people have bought their homes, staff have helped with home maintenance problems. Staff can also help with learning about the community and how to become a good neighbor.

Agencies have helped many people rent apartments, houses, and condominiums.

Many people with disabilities can't afford or just don't want to buy a house, but they still want to live in a place of their own. Agencies have helped many people rent apartments, houses, and condominiums. Staff have helped people with rental lease agreements, maintenance concerns, and problems with landlords and neighbors.

Whether people with disabilities live in their own places or in homes operated by agencies, they often live with other people with disabilities. Agencies are giving

people more of a say in who they live with, and are also thinking more about people's likes, dislikes, and personalities when finding housemates.

Many agencies are also giving people with disabilities more input in the hiring of staff who will work with them. Agencies screen people who want to work as staff to make sure they meet the requirements of the job, but before they are hired, they must get the approval of the people with disabilities who live there. This "attitude" change shows that agencies respect the people they serve. Other examples of respect include staff knocking on a person's door before entering, asking permission before using a person's phone or to smoke a cigarette, and helping people to display their personal possessions and decorate their rooms as they choose.

Many agencies are trying very hard to support people with disabilities as best they can, and to truly listen to and support the people they serve. Unfortunately, there are still some well-meaning agencies that try to control the lives of the people they serve. In the area of housing, there is still a long way to go so that agencies can truly support people living in the homes of their choice.

Tom is the Executive Director of Family Services for Cooperating Community Programs. 6b

This Old House

By the 1960's some institutions had nearly 6,000 people living in them.

Once considered a great idea in education, the institutions had become warehouses for people with disabilities.

The state institutions - large facilities that have housed thousands of people with developmental disabilities - are slowly being closed. After more than one hundred years, our society no longer views institutions as proper places for people with disabilities to live and grow. But for thousands of people institutions are still "home."

Around the time our country began, many people with disabilities were placed into institutions, sometimes along with criminals, drunkards, runaways, people who were sick or poor, and other people who were considered "different." These institutions were for people who did not "fit" into society. Beginning around the year 1850, our country built large facilities for persons with developmental disabilities, often called "schools for the feeble-minded." A common view at this time was that persons with mental retardation were sick, and needed to be treated. With good intentions, many of these institutions provided schooling and training. Another common view was that persons with mental retardation should not live with nondisabled people. These institutions had hundreds of people living in them. They were run by doctors and medical staff, and were usually located in the country, away from the community.

Gradually, the institutions for persons with developmental disabilities became

more crowded. Even though they were only supposed to keep people for a limited time—like going away for school—the institutions became the permanent home for thousands of people. The institutions grew as segregated communities, meaning that people with disabilities lived only with other people with disabilities; the rest of the community was kept out.

As the institutions became crowded, the living conditions became horrible, with people wearing few if any clothes, and in some cases being treated no better than animals. By the 1960s, some institutions had nearly 6,000 people living in them. Once considered a great idea in education, the institutions had become warehouses for people with disabilities. It was not unusual for over 100 people to occupy one room, with only a few staff people to provide assistance.

With the hard work of parents who were horrified at the conditions of institutions, people slowly began to move out into the community. Since the 1960s, the number of people living in state institutions has dropped from 200,000 to around 70,000. Many people have moved into group homes. Some people live independently in their own apartments or houses. Others have moved into small institutions—sometimes called large group homes—with close to 100 other people.

But not everyone has moved into the community. Over 70,000 people still live in public institutions, and thousands more live in private institutions. The states of New Hampshire, Vermont, and Rhode Island have closed their institutions, and other states are following slowly. Some think that people with severe disabilities should stay in institutions, and are fighting to keep them open. Many self-advocacy groups have helped to close institutions by speaking up and telling their legislators that, regardless of the level of disability, living in institutions does not give people the opportunity to learn from peers, and that living in

Regardless of the level of disability, living in institutions does not give people the opportunity to learn from peers, and does not provide a "normal" environment.

The Keys are Mine!

by Kevin Otley

When I lived at the Lake Owasso state institution in Minnesota, you had to ask for everything: "can you let me out?," "can I have a can of pop?," "can I stay up a little bit longer?"

When I moved into a group home, I had to follow all of the rules. I had to go to bed at a certain time, and when I was in bed, I had to be asleep: that was that. I lived with two other guys. We were being watched all the time, 24 hours a day, seven days a week.

Two years ago I got married. My wife and I moved into our



own apartment. Now that I have my own place, I make the decisions. I have my own keys. I can let myself out, and let myself back in.

Now I can come and go when I want. I can make my own food, and I decide whether I want to have breakfast or lunch, or when I'm ready for a snack. We can invite friends to stay over. My wife and I decide when the staff come over. They help us with some things, but we make our own decisions.

Kevin is a self-advocate and member of Advocating Change Together in St. Paul, MN.

Becoming Independent

by Brian Robert Bell

My name is Brian Bell. I used to live near Montreal in a small city called St. Lambert. I lived with my parents until I was twenty years old and then moved to Toronto into a large house which helped me get independent. It was called Lorimer Lodge. It was kind of like a fraternity house which taught independent living. There were 14 young men and women who were learning how to live on their own and how to get along in the community. They also taught us how to look for jobs and understand the value of working.

I lived at Lorimer Lodge for two years and then moved into a house with five other people. We all had assignments. For example, one person would take care of the living room, another person would do the kitchen. In a house with five people, there's a lot of work to do. The counselors — the people who worked there — were okay, but some of the other people acted inappropriately. I didn't always like what I saw. I didn't like the rules, either. I like to ice skate, and this is very important to me. I didn't like having to be home at a certain time every night when I could be out skating. I also didn't like people getting into my private things. I like being independent, and not having people bother me a lot.

Living on my own is not as easy as I thought, but it's much easier than living with a lot of other people. I feel free now, and am much happier.

After two years, I decided I wanted to live on my own. I now have a large one-bedroom apartment in Toronto and have been here for the past six years. The rent on the apartment is subsidized by the government and is fixed to my income. I pay twenty-five percent of my salary. Living on my own is not as easy as I thought, but it's much easier than living with a lot of other people. I feel free now, and am much happier. When I have problems, such as figuring out my bills, my family and friends help me. They help me to understand my finances, and also give me moral support.

Some day, maybe in five years, I'd like to have my own house. I'd like to live on Ward Island, which is a really quiet, peaceful place. For now, I want to ice skate and stay busy.

Brian is a highly-skilled figure skater and self-advocate living in Toronto.

CoHousing offers Support and Independence

There is a new movement in housing called CoHousing that works to build community. CoHousing is an idea in housing that allows people to share resources, such as a large community kitchen, gardens, guest rooms, a laundry, a workshop, and child care facilities, while also giving people their own homes, with their own resources, so they can also have privacy.

CoHousing developments work to bring together people who share similar values and provide them with the supports to help each other. All of the people who live in CoHousing developments have power over where they live: they make decisions about how their community works, and they share the responsibility of helping one another.

Most housing developments in our country do not help build a sense of community. Houses are often built facing a street, with fences around their back yards. Often neighbors do not know each other. Everyone in a typical neighborhood mows their own lawn, shovels their own sidewalk, cooks their own meals, and cares for their own children. With CoHousing, everyone who lives in the development can share in these tasks. People still have privacy in CoHousing, and may choose to make their own meals or do their own home repairs, but they have the support of knowing they can share meals, yard work, or other tasks. Homes in CoHousing are built

around a "common house," which includes the community kitchen and other facilities. Unlike homes in the city, the homes in CoHousing developments do not have a lot of streets running through them. Instead, they have more open spaces for community activities and provide a safer place for everyone.

Because CoHousing offers so many supports, it is a natural choice for self-advocates who are ready and financially able to own a home. Self-advocates can have the help and support of their community, and also the independence of having their own place to live. By making decisions on how the housing development operates, self-advocates in CoHousing become full and valued citizens in their community. CoHousing is also well-suited to extended families, where older parents can live with or near their children, and where young children can have the support of a large family.

CoHousing is a new idea in the United States. There are now over 70 CoHousing groups forming in many parts of the country and some are almost completed. To find out more about CoHousing in Minneapolis/St. Paul, call (612)930-7580.

In the next issue of VOICEPRINT

Media Images

People with developmental disabilities have often been portrayed as child-like in television and the movies. Instead of seeing self-advocates speaking up for their rights, we often see the images of men and women who do not act assertively and who do not make their own decisions. What movies have shown positive images of persons with developmental disabilities? What movies make all of us angry? Self-advocates will talk about what they think about media images of people with disabilities, and what can be done to show more realistic images.

Tell us what you think!
Write to us at:

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Please submit your letters or stories before January 6th, 1995.

What do you think?

If you would like to respond to an article in VOICEPRINT, please write or call us. We will try to print all responses in the next issue.

Self-Advocacy Documentary Available on Video

S*ticks and Stones: The Self-Advocacy Movement in Minnesota*, is now available on video cassette through Advocating Change Together. *Sticks and Stones* traces the rise of self-advocacy through the stories of people who fought for their human and civil rights — and the rights of others with developmental disabilities — and learned to speak for themselves. The documentary aired on Public Television in Minnesota, and was awarded Best Documentary at the 1994 Minnesota Community Television Awards.

To order a copy of *Sticks and Stones*, call ACT at (612) 641-0297. The cost is \$30 for individuals and \$100 for organizations. The program is closed captioned.

About Voiceprint...

VOICEPRINT is a publication for self-advocates and others who are concerned with improving the working and living conditions of people with developmental and other disabilities. VOICEPRINT publishes stories by and about self-advocates and the issues that concern them. The goal of this publication is to serve as a resource for self-advocates by printing ideas and stories that often go unheard. It is our hope that these articles and stories help self-advocates (and other cultural workers) to change the negative attitudes in society toward disability.

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